

DOWN SYNDROME CHECKLIST: BIRTH

Learning that your child has Down syndrome can be overwhelming. This checklist was developed to help guide you through the first steps.

Contact the Trisomy 21 Program

The **Trisomy 21 Program** assesses the growth and development of children with Down syndrome. Our team offers physical, occupational, and speech therapy evaluations and social work consultations. We will review your child's medical history, therapies, and medications as well as his mental health, social, educational, and medical needs. We will make recommendations based on our findings and make sure your child is up-to-date on all recommended testing. We do **NOT** replace your primary care provider or any specialist, but we are happy to work with them in order to provide your child with the best possible care.

Please call the Trisomy 21 Program Coordinator at (267) 426-5283 (option 1) at any time to complete an initial intake.

Register for early intervention

Early intervention (EI) is a group of services provided to children who may have developmental delays. The services most common for babies with Down syndrome are physical therapy, occupational therapy, and speech therapy.

- ✓ Pennsylvania residents, call CONNECT at (800) 692-7288
- ✓ New Jersey residents, call the New Jersey Early Intervention System at (888) 653-4463
- ✓ Delaware residents, call the Office of Prevention and Early Intervention at (302) 892-4576

Apply for Supplemental Security Income (SSI) and Medical Assistance

Supplemental Security Income (SSI) is money provided by the Federal Government to help people with disabilities. The amount of money provided is based on family income.

Medical Assistance is health insurance and it will help cover at least some of your child's medical costs. If your child has private health insurance, MA can be back-up insurance to cover costs that are not covered by your primary insurance. MA may also cover therapy that is not provided through early intervention. In addition, MA provides Pennsylvania families with Special Needs Coordinators who will help you understand the health care system.

Contact CHOP's Department of Family Health Coverage at 1-(800) 974-2125. A coordinator who works with families from Pennsylvania and New Jersey will walk you through the entire process.

Take a copy of the following to your child's primary health care provider:

- ✓ The *Down Syndrome Health Care Guidelines* – provided in the folder and available at www.ndss.org
- ✓ Contact information for the Trisomy 21 Program
 - Phone: (267) 426-5283
 - Website: <http://www.chop.edu/service/trisomy-21/home.html>
 - Email: trisomy21@email.chop.edu
- ✓ Growth charts for children with Down syndrome – provided in the folder and available at www.ndss.org

DOWN SYNDROME CHECKLIST: 3 MONTHS+

Discuss the following Down syndrome health care guidelines with your primary care provider:

Schedule an echocardiogram with a pediatric cardiologist

- WHAT?** An echocardiogram is a procedure that creates pictures of your baby's heart. It is used to diagnose and rule out heart defects.
- WHY?** Babies with Down syndrome are sometimes born with heart defects. It is important to identify any cardiac issues as soon as possible so treatment options can be discussed.
- WHEN?** All babies with Down syndrome should have an echocardiogram **by 3 months of age**.
- HOW?** If your baby did not receive an echocardiogram at the hospital before being discharged home, you can schedule an echocardiogram through a pediatric cardiology department. If you would like to make an appointment at CHOP, you can contact the cardiology department at (215) 426-4040.

Make an appointment with a pediatric audiologist

- WHAT?** An audiologist is a health care professional who specializes in ears. S/he is trained to identify, diagnose, treat, and monitor hearing problems.
- WHY?** The ability to hear affects the ability to speak, so it is important to have your baby's hearing checked.
- WHEN?** Your child should receive a newborn hearing screen with an audiologist **by 3 months of age** (this is in addition to the newborn hearing screen that is routinely done before leaving the hospital). All babies should see an audiologist every 6 months until age 3 and then yearly.
- HOW?** You can schedule an appointment with any audiologist. If you would like to make an appointment at CHOP, you can contact the audiology department at (800) 551-5480.

Make an appointment with a pediatric ophthalmologist

- WHAT?** An ophthalmologist is an "eye doctor". S/he can assess your child's vision and diagnosis and treat eye or vision problems.
- WHY?** Many vision problems can be easily corrected with glasses or other simple treatments.
- WHEN?** All babies with Down syndrome should receive an ophthalmological evaluation **by 6 months of age** and then yearly.
- HOW?** You can schedule an appointment with any pediatric ophthalmologist. If you would like to make an appointment at CHOP, you can contact the ophthalmology department at (215) 590- 2791.

Schedule a thyroid function test

- WHAT?** Thyroid hormones play an important role in growth, development, and metabolism. Thyroid levels are checked with a blood test.
- WHY?** Children with Down syndrome are at a higher risk of having abnormal thyroid levels, so it is important that your child's thyroid levels be checked regularly.
- WHEN?** All babies with Down syndrome should have their thyroid levels tested **at birth, at 6 months of age, at 1 year of age**, and then yearly.
- HOW?** You can schedule an appointment with your child's pediatrician's, CHOP, or another lab to have your baby's thyroid level checked.